

Demonstration of parent training to address early self-injury in young children with delays

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Abstract

Individuals with intellectual and developmental disabilities (IDD) are at a high risk for engaging in self-injurious behavior (SIB). Prognosis is poor when SIB emerges early. Limited research exists on interventions teaching parents how to manage their young child's SIB. This investigation assessed the feasibility of adapting an applied behavior analytic parent training program with 11 parents of children 1-5 years of age with IDD and SIB. Quantitative and observational measures were used to assess outcomes; semi-structured interviews assessed caregiver satisfaction. Outcomes yielded preliminary data suggesting the adapted curriculum was feasible and acceptable to parents. Initial efficacy outcomes yielded decreases in SIB and observed negative parent-child interactions on pre- and post-measures. Qualitative data provided areas for further curriculum refinement.

Keywords: self-injury; parent training; applied behavior analysis; developmental delay; young child

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Self-injurious behavior (SIB) is one of the most challenging problem behaviors to treat, especially when it occurs in individuals with intellectual and developmental disabilities (IDD). Occurring in 20% or more of adolescents and adults with IDD, SIB refers to a class of self-directed, repetitive behaviors that have the potential to result in physical injury (Rojahn, Schroeder, & Hoch, 2007). Examples of SIB include head banging, self-biting, self-scratching and hand mouthing. SIB is often chronic in this population; most who engage in SIB in childhood continue to do so well into late adulthood (Taylor et al., 2011). The vast majority of those with IDD who engage in SIB have done so since childhood (Berkson & Tupa, 2000; Sturmey et al., 2006; Holden & Gitlesen, 2006). Factors associated with an increased risk for SIB include severe or profound IDD (McClintock, Hall, & Oliver, 2003); significant sensory or physical disability (Murphy et al., 2005); expressive or receptive language difficulties (Richards, Moss, Nelson, & Oliver, 2016); and certain genetic disorders (Schroeder, Reese, Hellings, Loupe, & Tessel, 1999).

Those with IDD who engage in SIB experience a host of negative outcomes (Rojahn et al., 2007), as SIB carries significant health risks, including lacerations/fractures, recurrent infections, physical malformations, detached retinas/blindness, and in extreme cases, death. Consequences for engaging in SIB include restricted educational and vocational opportunities, social isolation, limited community-based activity, costly medical or residential care, and restrictive treatment practices (e.g., physical holds, seclusion/time out, loss of personal property).

Recent data suggests that early, non-threatening (i.e., no tissue damage) forms of SIB may occur in young children with IDD. Fodstad, Matson, & Rojahn (2012) found that in a sample of very young children (around 10-12 months) with IDD, approximately 18.3% were

engaging in SIB, including milder forms of eye poking, self-hitting, and head banging. Other researchers have found similar data on early SIB indicating that approximately 15 – 30% of children under 5 years of age with IDD exhibit early forms of SIB (Berkson, Tupa, & Sherman, 2001; Dimian et al., 2017; Schroeder et al., 2014). Thus, even very early in life, SIB occurs in children with IDD.

In addition to several risk factors, there are many theories that have been proposed to account for early SIB emergence including developmental, biological or neurochemical, and behavioral pathways to adaptation (see reviews by Cataldo & Harris, 1982; Richman, 2008; Rojahn, Schroeder, & Hoch, 2007). The behavioral theory posits that early, non-threatening behaviors (e.g., eye touching/rubbing) are shaped into more severe and frequently occurring acts (e.g., eye gouging) via how others in the child's environment immediately respond when the behavior occurs (Guess & Carr, 2001). For the very young child, their parent/family interactions are their main socializing agents. Family processes have been shown to influence the emergence of behavior disorders in young children without disabilities (Kumpfer & Alvarado, 2003), with negative parent-child interactions serving as salient risk factors for behavioral problems (Floyd et al., 2004; Patterson, 1998). Others have suggested there is a relationship between caregiver stress, use of appropriate parenting skills, and child behavior problems over time (Baker et al., 2003; Goldstein, Harvey, & Friedman-Weieneth, 2007; Gondoli & Silverberg, 1997). While this relationship may not adequately address other related environmental or biological factors that are likely related to behavioral emergence, teaching parents/caregivers appropriate strategies to decrease SIB when it first emerges may ultimately decrease this behavior and its worsening over time.

Behavioral interventions, especially those based on applied behavior analysis (ABA), are effective at reducing SIB as well as other negative behaviors, and increasing adaptive behavior related to the behavior's occurrence – including leisure/play skills, functional communication, attention allocation, and social interactions (see Furniss & Biswas, 2012 for a more thorough review). For this discussion, we are limiting our scope to curriculum-based parent training that has been shown to be cost-effective and includes didactic learning and intervention development experiences for the parents as opposed to more intensive, therapist-driven, or resource-dependent parent training approaches that have been described in behavior analytic literature (e.g., Kurtz et al., 2003; Wacker et al., 2005). Behaviorally-based parent training has long been used with children without IDD (Webster-Stratton, 2010; Eyberg, 1992; Sanders, 1999) and older children with IDD (Feldman & Werner, 2002; Matson, Mahan, LoVullo, 2009; McIntyre, 2008). Many curriculum-based parent training programs focus on increasing children's adaptive behavior, but few place significant attention on decreasing problem behaviors. In a recent randomized control trial, Bearss and colleagues (2015b) found an ABA-based parent-training curriculum (RUBI; Bearss and colleagues, 2015a) resulted in greater reductions in irritability and noncompliance for children with autism spectrum disorder and disruptive behaviors compared to parent training on autism-related topics. The active parent-training program taught parents behavioral strategies tailored to their child's specific behavior problems and included direct instruction, video examples, practice activities, role play/coaching, and weekly homework. While results were promising, none of the children had SIB as their targeted problem behavior (Mitchell, Bearss, & Scahill, 2014; K. Bearss & L. Scahill & K., personal communication, February 10, 2018) and the curriculum was primarily geared for children with autism as opposed to children with IDD on a broader scale.

Presently, there is little research on parent-training curriculum targeting SIB in very young children (< 5 years of age) with IDD. Furthermore, treatment for SIB in those with IDD generally occurs in adolescence at which point behavior is already severe and often causing tissue damage (Rojahn et al., 2007). Knowing these behaviors occur early in life (Fodstad et al., 2012), early intervention could prevent and diminish the impact of SIB across development. An evidenced-based treatment for very young children with IDD and SIB would be a step towards ultimately improving the trajectory of early problem behaviors. Intervening at the first signs of SIB would lessen the likelihood that response-reinforcer relationships would become well-established and result in more difficult behaviors to treat.

Aims of the Current Study

The present investigation was designed to conduct a field-initiated development project to adapt the Bearss and colleagues (2015a, b) protocol for parents of young children with IDD and early SIB. Quantitative and qualitative methods were used to evaluate the experiences of caregivers across the parent training intervention. Given the positive outcomes shown by Bearss and colleagues, it was hypothesized that caregivers would report satisfaction and their children would experience improvement on targeted behaviors.

Method

Design

This study was approved by the study-site Institutional Review Board. The Self-Injurious Behavior-Parent Training (SIB-PT) program was a 3.5 month, open treatment trial that consisted of 11 core sessions. The intervention was carried out by a therapist who had met research-level treatment fidelity criteria of the Bearss et al parent training protocol. Outcome measures and a parent-child observation were administered at baseline (1-2 weeks prior to SIB-

PT) and post-treatment (1-2 weeks after SIB-PT). SIB-PT was provided at no charge. Families were provided a small amount of compensation (up to \$120) to cover ancillary costs (e.g., gas, food); parking was provided at no charge.

Participants

Inclusion and exclusion criteria. Participants included parents/legal guardians and their children ages 1 to 5 years of age with IDD and early SIB who met the inclusion and exclusion criteria listed in Table 1. Children were also required to be in a stable behavioral or educational program and either on no medication or a stable dose for at least 90 days prior to baseline with

[Insert Table 1 about here]

no anticipated changes for the duration of the trial. This criterion was intended to ensure that changes in child behavior were due to the study intervention and not to a new medication or service the child was receiving outside of the study.

Recruitment and Screening

Families were referred through various providers throughout a large, urban health system in the Midwest United States and recruited through advertisements in local magazines. Twenty-three potential participants were initially screened during a brief phone call. If they met the study inclusion criteria (see Table 1) during initial screen, they were seen for clinical intake. At this appointment, the intervention was explained in further detail and offered as an alternative to routine clinic care. Those who agreed to participate signed consent documents and completed the assessment.

Of the 23 families referred, approximately 17 parent-child dyads met criteria and were invited for a clinical intake assessment. Of those 17, 13 families completed the intake/baseline assessment. The four families who did not complete the initial assessment did not attend their

intake appointment. Of the 13 parent-child dyads that enrolled, two did not complete the intervention and were not included in analyses. The two families who dropped out prematurely before their first intervention appointments did so either due to a prolonged medical emergency or moving out of state.

SIB-PT Intervention

The SIB-PT program was adapted from the Bearss et al (2015) RUBI parent training curriculum program. For the purposes of this pilot, only core sessions were used, including main content areas of antecedent-based strategies, praise/reinforcement, planned ignoring, limit setting/appropriate commands, alternative and appropriate skills teaching and generalization. Slight modifications were made to focus on non-ASD delays and early SIB. Modifications mainly involved changing terminology (i.e., from ASD to developmental delays) and re-writing in-session vignettes or homework to focus more on SIB. See Table 2 for a brief outline. 60-90 minutes sessions occurred 1:1 in a hospital-based, outpatient clinic.

[Insert Table 2 about here]

To ensure the parent training curriculum was implemented as intended, a treatment manual was followed with session checklists, completed by the therapist at the end of each session. To ensure that each parent received the same content, the therapist read from verbatim scripts that were developed for each session. Additionally, each treatment session used direct instruction, video examples, practice activities, and rehearsal (role play) with feedback to promote skill acquisition. Parents were asked to implement behavior intervention techniques individualized for their child based upon that week's topic content for homework. The therapist worked with the parent to develop each behavior intervention technique and to ensure that it was manageable, specific to the primary targeted behavior, and was related to the hypothesized

maintaining function(s) of their child's self-injury. A functional behavior assessment had been previously completed during the initial baseline visit by the therapist, and parents had also independently completed an antecedent-behavior-consequence log as part of their homework for session 1; these were completed to assist with identifying variables related to contingencies related to maintenance of the child's self-injury (further information regarding functional assessment can be provided upon request). At the completion of each session, the therapist provided the parent a written copy of their child's current behavior plan, any relevant visual aide, and homework logs/handouts to track their progress implementing that week's prescribed skill. An independent observer collected the therapist's curriculum implementation integrity data during 30% of sessions by indicating the presence or absence of each treatment step. One hundred percent of intervention curriculum components were implemented as intended.

Subject Characterization Measures

Demographic data form. Form developed to collect child's gender, age, ethnicity, and school placement, as well as parent age, education and employment, living arrangement, and income.

Medical/Psychiatric history and services questionnaire. This caregiver questionnaire provides information on child's: (a) illnesses, surgeries, and hospitalizations, (b) health and psychiatric problems, (c) developmental delays, and (d) medications for problem behavior or other conditions.

Preliminary Feasibility Outcome Measures

Weekly parent feedback. Data were collected using a 7-point Likert-type rating scale (e.g., 1 = not helpful at all to 7 = very helpful) at end of meeting to assess parents' beliefs that the specific information provided to them was useful and likelihood they would implement the

strategies. They provided ratings on the four categories: content, videotapes, teaching, and handouts/skills training.

Consumer Satisfaction Questionnaire. An adaptation of the Consumer Satisfaction Questionnaire (CSQ; Forehand & McMahon, 1981) was utilized to assess caregivers' perceptions of the therapist's effectiveness, materials used, usefulness of content, and effectiveness of program methods yielding five summary scales based upon a 7-point Likert-type caregiver rating (e.g., "very strongly disagree" to "very strongly agree"): overall program satisfaction, program usefulness, leader/therapist satisfaction, satisfaction with teaching tools, and specific parenting strategies.

Homework completion. Data were collected on caregiver completion of homework. That is, if a caregiver returned a completed homework log at the subsequent session, they were classified as being a "homework completer." Additionally, if a caregiver verbally reported that they practiced the skill and were able to provide clear examples of implementing the prescribed skills, they were also classified as a homework completer. Homework "noncompleters" were coded if they failed to return a completed homework log, were unable to provide clear examples of using suggested skills, or indicated they did not practice the skill.

Time to complete intervention. Data were collected on the number of weeks parents required to complete the intervention.

Semi-structured interview of caregiver acceptability. Qualitative methods were used to assess caregivers' experience with the intervention through semi-structured interviews conducted at post-treatment after the caregiver completed their satisfaction survey (i.e., CSQ). The interview, completed by an independent evaluator explored (a) the caregiver's overall experience; (b) perceived effectiveness of SIB-PT, (c) suggestions for improvement, and (d)

usefulness of each aspect of the program. The conversation between the evaluator and caregiver lasted approximately 30 minutes; the interview was audio-recorded and transcribed in full at a later date.

Preliminary Efficacy Outcome Measures

Aberrant Behavior Checklist (ABC). The ABC (Aman et al., 1985) is a 58-item caregiver-report measure with five subscales: Irritability, Social Withdrawal, Stereotypies, Hyperactivity, and Inappropriate Speech. Items are scored based on how much of a problem the individual's behavior has been over the past month using a 4-point Likert-type scale (0 = not a problem through 3 = problem is severe in degree). Of particular interest to this study, were the SIB specific items, "injures self on purpose," "deliberately hurts himself/herself," and "does physical violence to self." A SIB-item level summary score was tabulated for each child participant with a max score of 9.

Behavior Problems Inventory-01 (BPI-01). The BPI-01 (Rojahn et al., 2001) is a 49-item problem behavior rating instrument with three subscales: Self-injurious behavior, Stereotypies, and Aggressive/Destructive Behavior. Items are scored on a 5-point Likert-type frequency (0 = never to 4 = hourly) and a 4-point Likert type severity (0 = no problem to 3 = severe problem) scale. Only behaviors that have occurred at least once during the past two months are scored. Of particular interest to this study was the Self-Injurious Subscale that describes various self-directed behaviors, including "pulling finger or toe nails", "self-biting", and "inserting objects in body opening". There is an "other" item where parents can add additional self-injurious behaviors. For this study, only frequency was used in statistical analyses.

Self-Injury Trauma Scale—SIT Scale. The SIT scale (Iwata et al., 1990) is a clinician-completed scale to quantify visible injuries caused by SIB, including indication of SIB topographies and any evidence of healed injury, documentation of the location and severity of injury, as well as a Number Index (max score of 5 = 17 or more SIB-related wounds), a Severity Index (max score of 5 = two or more SIB-related contusions), and Estimate of Current Risk (0 = low, 1 = moderate, or 2 = high).

Clinical Global Impressions: Improvement Scale (Parent Ratings). The CGI-I (Guy, 1976) is 7-point Likert-type scale designed to measure overall improvement from baseline. Scores range from 1 (Very Much Improved) to 7 (Very Much Worse). The CGI-I was used by the therapist, as well as parents, to assess overall response to treatment for the primary SIB behaviors targeted. Given the short time frame between last intervention session and post-treatment assessment (i.e., 2- weeks) and the length of implementation time some behavioral strategies may take to engender substantial change, children given CGI-I scores of 1 (Very Much Improved) or 2 (Much Improved) were classified as *positive responders*; all other children were classified as *non-responders*. We only report parent CGI-scores in our outcomes: while CGI scores are traditionally completed by an independent evaluator, parent CGI was more used as an additional measure of satisfaction with outcomes observed and with the curriculum.

Parenting Stress Index-Short Form (PSI-SF). The PSI-SF (Abidin, 1990) is a caregiver-completed questionnaire with three scales: Parental Distress, Difficult Child Characteristics, and Dysfunctional Parent-Child Interaction. A PSI total score of ≥ 88 (85th percentile) is considered clinically significant. The PSI-SF was used to screen for possible maladaptive parent coping characteristics prior to intervention initiation, and to look at changes in parental stress due to their participation in this study.

Parent and child observed behavior. A 15-minute observational system loosely based on the work by Phaneuf & McIntyre (2007) and Johnson et al (2009), was developed for the current study with observation categories derived based on the SIB-PT content areas, using 10-s partial-interval coding for presence or absence of seven maladaptive caregiver behavior categories (inappropriate play behavior, intrusion on child's independence, attention/reward for child inappropriate behaviors, inappropriate command, lack of follow through, criticism, and aggression) and maladaptive child behaviors (aggression, disruptions, negative vocalizations, self-injurious behavior). During this observation, parents were asked to complete 3 naturalistic play-based scenarios: free play (10 minutes), clean –up (2 minutes), structured activity (3 minutes). Prior to the baseline observation, parents identified 3-5 toys (e.g., cars, dolls) their child preferred from a list of available items for the free play condition, and one activity they often completed with their child (e.g., puzzles); these items chosen remained the same at the post-treatment play-based observation. Other items present during the observation included a child-sized table and chairs set, a laundry basket, and a video camera. Parents were instructed to interact with their child and respond to behavior like they usually would at home. To limit interference, the primary observer instructed the parent via a bug in the ear audio-receiver when each probe began or ended. Due to low base rates of child maladaptive behavior across the observations, a combined maladaptive index of child behavior was calculated. Of interest to this study and to demonstrate preliminary efficacy on increasing appropriate parenting skills, only a combined maladaptive index of caregiver behavior will be reported here. An interval can be coded as “positive” for more than one maladaptive behavior category. The combined maladaptive index is the number of intervals containing a maladaptive behavior converted into a

percentage of total intervals. Appropriate child-directed praise and descriptive play comments were coded using frequency coding.

The parent-child observations were videotaped and coded at a later date. Two independent, trained observers coded data during 80% of videotaped sessions using interval-by-interval agreement. Kappa coefficients were used to calculate inter-observer agreement for each category and for overall composites (κ s = .83 - .98).

Data Analysis

Preliminary feasibility and acceptance of the treatment was evaluated by computing weeks to completion, ratings of caregiver satisfaction (weekly and CSQ), outcomes from semi-structured interviews, and homework completion. Preliminary efficacy of SIB-PT included data from baseline and post-treatment assessments. Paired samples t-tests were performed on the primary outcome variables (ABC SIB-item score; BPI-01 SIB domain frequency and severity score; SIT Scale severity index). Exploratory analyses using paired-sampled t-tests evaluated the additional ABC and BPI-01 subscales and outcomes from the parent-child behavior observation. All a-priori assumptions of paired-sample t-tests were met. Due to the small sample size and exploratory nature of our study, Bonferroni corrections for multiple comparisons were not made. The necessity of Bonferroni corrections for non-confirmatory, small sample studies are debated (Tabachnick & Fidell, 2013) and in the present pilot we opted for reported the exact alpha-levels and effect sizes (Rothman, 1990; Feise, 2002) with $d = 0.2$ considered a small, $d = 0.5$ a medium, and $d = 0.8$ or above a large effect size (Cohen, 1992). Due to our modest sample size, effect sizes are interpreted conjointly with p -values.

Since the purpose of the qualitative analysis was to understand caregiver experiences throughout the SIB-PT intervention, a thematic analysis was performed on transcription notes

from individual interviews. The coding procedures followed Seale and colleagues (2004) guidelines for small-sample data: two independent reviewers made value judgements to determine the valence of caregiver comments with respect to a-priori content areas of overall experience, perceived effectiveness, suggestions for improvement, and usefulness of program aspects. Valence classifications were made by the first author and a trained research assistant to determine whether comments were positive, negative, or neutral in nature. Inter-rater reliability of the initial ratings was 91.25%. In those instances where raters did not agree on the caregiver's valence, a third independent reviewer evaluated the content, clarified coding definitions with the coders, and made a final classification judgment. Responses were tallied to give overall rating of caregivers' opinions: caregivers with a positive opinion had a majority of positive statements across all four content areas; caregivers with a negative opinion had a majority of negative statements across all four content areas; and caregivers with a mixed opinion had an array of positive, neutral, and negative statements with no valence being a majority.

Results

Demographic Information

Main demographic variables. Tables 3-4 provide a summary of the main demographic variables. A total of 11 children ($M_{age} = 44.84$ months; $Range_{age} = 17.88 - 72.84$ months) and their parents participated in the intervention. Most children were living with biological mothers

[Insert Tables 3 – 4 about here]

($N = 9$; 81.8 %). Two children were living with adoptive parents. Of the parents involved in the SIB-PT program, the majority were mothers ($N = 9$; 81.8 %). The average distance from the clinic was 35.91 miles ($Range = 3 - 141$).

The children engaged in a wide variety of self-injurious behaviors at baseline. Figure 1 lists self-directed/self-injurious behaviors parents endorsed at baseline as being a primary concern and desired focus of intervention. The most frequently identified SIB was head banging

[Insert Figure 1 about here]

(72.7%; $N = 8$). Other behaviors identified as primary target were as follows: self-pinching (54.5%; $N = 6$); self-scratching (54.5%; $N = 6$); hand/arm biting (45.4%; $N = 5$), eye rubbing (18.2%; $N = 2$); head hitting (18.2%; $N = 2$); head rubbing (9.1%; $N = 1$); self-gagging (9.1%; $N = 1$); non-head-directed body slapping (9.1%; $N = 1$); and hair pulling (9.1%; $N = 1$).

School services. Seven children were enrolled in school, with five attending developmental preschool, one attending an ABA center, and one attending a non-traditional school. Children were spending an average of 13.5 hours in school each week (Range = 0 – 35). In addition, we gathered information on services children were receiving in school. Two students had 1:1 aides, averaging 26.25 hours per week. Five children had a Behavior Support Plan (BSP). Students were receiving a variety of services in school including: speech therapy (64.0%; $N = 7$), occupational therapy (55.0%; $N = 6$), physical therapy (36.0%; $N = 4$), social skills training (18.0%; $N = 2$), play therapy (9.1%; $N = 1$), and direct instruction with aide/behavior therapist (18.0%; $N = 2$).

Other services. Six children were receiving services in the community for an average of 2.33 hours per week (Range = 1 – 3). Services included: speech therapy (45.0%; $N = 5$), occupational therapy (45.0%; $N = 5$), physical therapy (36.0%; $N = 4$), play therapy (9.1%; $N = 1$), and direct instruction with aide/behavior therapist (18.0%; $N = 2$).

Preliminary Feasibility Data

Parent ratings indicated that, on average, all aspects of the sessions were helpful. The mean weekly SIB-PT session ratings for each of the four areas were: content 6.16 ($SD = 0.28$); videotapes 6.01 ($SD = 0.57$); teaching 6.47 ($SD = 0.32$); handouts/skills training 5.60 ($SD = 0.34$). On the end of treatment CSQ, the specific categories and mean ratings were as follows: overall program 6.25 ($SD = 0.50$); program usefulness 6.43 ($SD = 0.32$); leader/therapist 6.72 ($SD = 0.14$); teaching tools 5.47 ($SD = 0.87$); and specific parenting strategies/techniques 5.12 ($SD = 0.87$). The average score across all 46 items was 5.97 ($SD = 0.47$) indicating a moderately high level of satisfaction. On average, 95.0% of parents across all sessions were coded as “homework completers” either due to returning completed homework logs or via a clear verbal report of skill usage. Finally, parents took approximately 13.23 weeks ($SD = 0.97$) to complete the 11-week SIB-PT intervention.

Qualitative findings. Results from the semi-structured feedback interviews indicated that 54.5% ($N = 6$) of the caregiver interview responses were positive; 27.2% ($N = 3$) were mixed; and 18.2% ($N = 2$) were negative. All caregivers expressed enthusiasm for participating in a study that was focused on reducing early SIB. Those who were classified as having a positive view of the intervention indicated they learned many strategies that were helpful for their child, and they felt they had become better equipped to manage their child’s SIB and other behavioral issues. One parent went so far to say she “appreciated that someone had (for once) been as concerned about her child’s SIB as she was” and she felt that given her child’s young age (2 years, 2 months at the baseline assessment) she had been told too often “wait, he will grow out of it.” Other parents reported they liked how the intervention included a didactic/learning component and was not just focused on teaching parents “what to do” but rather “why your child does this behavior” and “why these strategies could help.” Caregivers indicated they enjoyed

having handouts and copies of their child's updated behavior plan given to them on a weekly basis, and they perceived the therapist worked with them to develop strategies and visuals that were individualized for their child.

While there were caregivers who were classified as having mixed or negative responses, they also provided valuable feedback and insight into how SIB-PT could be improved in the future. Caregivers raised concerns about having to complete modules not applicable to their child's specific behavioral needs (e.g., teaching skills) and having to learn and use strategies they perceived as not helpful or difficult to implement (e.g., planned ignoring, structured schedules or routines). Videos vignettes used from the original Bearss et al (2015) curriculum were reported to not always be applicable as they used older and highly-verbal children as actors. Caregivers indicated it was often hard to make weekly clinic appointments and that the intervention (i.e., 11 weeks) was somewhat lengthy. Some of these caregivers suggested alternative formats or learning methods (e.g., telehealth, online modules) should be considered.

Preliminary Evidence of Efficacy

Table 5 displays mean ABC scores, BPI-01, PSI-SF, SIT scale scores and outcomes from the Parent-Child Observation at baseline and post. Statistically significant changes at post-intervention compared to pre-intervention were found across primary and secondary outcome measures with effect sizes ranging from 0.21 to 1.90.

[Insert Table 5 about here]

The mean parent SIB-specific item endorsement on the ABC decreased from 5.5 ± 1.70 at baseline to 2.75 ± 1.13 ($p < .001$, $d = 1.90$) at post-intervention. Similarly, parent frequency endorsements on the Self-Injurious subscale of the BPI-01 decreased from 21.75 ± 11.40 at baseline to 10.08 ± 6.05 ($p < .001$, $d = 1.28$) at post-intervention. Table 5 provides additional

scores on the ABC and BPI-01 – across the majority of subscales parents reported significant decreases in behaviors from baseline. There were no changes from pre- to post-intervention on the SIT scale overall risk estimate as all participants were rated as being as at a minimal risk of harm (score of 0) at baseline and at post-intervention.

On the CGI-I, 10 of 11 (90.9%) parents rated their child as having shown some improvement in their SIB since beginning the intervention at a 2-week post-intervention follow-up: 4 children were rated “minimally improved”, 4 were rated as “much improved”, and 2 were rated as “very much improved.” However, using our more stringent classification being a “responder” to treatment only 54.5% (i.e., 6 out of 11) caregivers indicated their child’s SIB was very improved to very much improved. The child who was classified as a non-responder was rated by their parent as showing “no change” in the primary SIB at post-intervention.

Looking across outcomes from the Parent-Child Observation, statistically significant changes occurred with respect to both child and parent behavior. Specifically, parental use of maladaptive interactive strategies decreased from $65.75\% \pm 16.60\%$ at baseline to $23.27\% \pm 13.65\%$ ($p < .001$, $d = 1.83$) post-treatment. Conversely, increases were observed in parents’ use of positive praise: they used praise $0.61 \text{ rpm} \pm 0.28$ at baseline versus 1.06 ± 0.41 ($p = .02$, $d = 0.34$) at post-intervention. Child observed maladaptive/problem behaviors decreased from $16.00\% \pm 13.62\%$ to $5.36\% \pm 5.61\%$ ($p = .04$, $d = 0.21$).

Finally, parents indicated similar stress levels at baseline ($M = 76.53$; $SD = 13.78$) and post-intervention ($M = 70.45$; $SD = 14.27$). It should be noted that scores above 88 on the PSI-SF total score are considered to be in the clinically significant range. Therefore, regardless of there not being significant changes observed, caregivers were reporting high, but not clinically significant levels of stress across their participation in this study.

Discussion

Findings support the adaptation of the parent training curriculum by Bearss and colleagues (2015) for young children with IDD and early SIB. Overall, SIB-PT was shown to be acceptable by parents, with an average of moderately high to high ratings across the weekly and overall satisfaction ratings. Eleven of thirteen enrolled families completed the intervention, and weeks taken to complete the intervention were not overly divergent from the 11-week program. Although the study was not designed to provide a rigorous test of the efficacy of the SIB-PT program, the preliminary results suggest the program may yield reductions in early and emerging SIB in young children with IDD. These findings may need to be interpreted with caution. First, our sample size is extremely small and generalizing our findings across children with early SIB and IDD and their parents may be premature. Second, our sample of child participants with SIB had significantly higher rates of challenging behaviors, as noted by mean baseline ABC-Irritability and ABC-Hyperactivity scores of 33.3 and 32.3, respectively when compared to those reported by caregivers in Bearss et al (mean scores were 23.7 [Irritability] and 29.5 [Hyperactivity]). The fact that our sample of children were rated as more behaviorally challenged may have contributed to our results not being as robust as other researchers who have used the RUBI program. Relatedly, it is unclear if the ABC or BPI-01 are appropriate measures to use for this young age. Despite decreases in parent-reported frequency and severity scores on these measures, SIB across child participants was assessed by the SIT Scale to be relatively benign. Furthermore, other researchers have found that the present ABC factor structure is unsupported in children less than 5 years of age (Schmidt, Huete, Fodstad, Chin, & Kurtz, 2013) and may over- or under-estimate parental concerns across some domains. However, other researchers have continued to use the ABC and BPI-01 in research and have found the measures to be useful

and valid for this young population (e.g., Mayo-Ortega et al., 2012; Rojahn et al., 2013).

Determining if the ABC and BPI-01 are sensitive to this early age range should be investigated further, or more appropriate measures of early SIB should be developed. Regardless of these measurement issues, by taking a more early intervention approach it would be easier and less costly to reduce mild forms of SIB as opposed to waiting until the behavior is more frequent or severe.

Decreases in maladaptive parenting strategies were also observed during the play-based dyad observation. More rigorous testing should be conducted (e.g., randomized control trial) with long-term follow-up to determine the utility of this treatment modality in decreasing early SIB and increasing positive parent behavior management strategies. Over time, parental use of positive parenting strategies could be more likely to reduce the risk of early and low-severity SIB becoming severe and chronic. Thus, by teaching parents how to better manage early aberrant behaviors using evidenced-based strategies could lead to global improvement in child behavior.

The qualitative data provided in-depth, subjective information about the participants' experiences in SIB-PT. Most families expressed satisfaction with the process in general and, in fact, recommended that SIB-PT be made more easily accessible to them and other families. Parent participants expressed appreciation for the collaborative, didactic component to the program which allowed them to not only learn the theory behind techniques but also work with a therapist to devise strategies that would suit their child and family. Parents felt supported by the therapist, but did note that being able to connect with other families in similar situations might increase their support/social network. Concerns regarding the high-level of stress involved in caring for a young child with IDD and SIB and limited sense of being able to manage those stressors were reported across parents. These concerns mirrored quantitative outcomes showing

that caregivers, on average, reported high (but not clinically significant) levels of stress at baseline and post-treatment. These outcomes are consistent with others who have found that behavioral parent training programs for children with IDD often do not adequately target caregiver distress unless they include components that specifically target family well-being and support (Singer, Ethridge, Aldana, 2007). Future extensions of SIB-PT should look at the utility of adding coping/stress management strategies to improve mental health and wellness for caregivers, as well as consider group formats. Finding additional ways to provide parents with support (access to community based services, knowledge about how to navigate disability services, advocacy, etc.) should also be considered as an additional component that could assist with caregiver well-being.

The present study is not a rigorous test of the efficacy of SIB-PT. While our findings are suggestive of the intervention's important role in decreasing early SIB in very young children with IDD and increasing more adaptive behaviorally-based parenting skills, outcomes are preliminary. The small sample size, lack of control group, and pre-posttest design limit the conclusions that can be made. An extension of this pilot study should incorporate a control group (e.g., treatment as usual), as well as include more sophisticated methods to evaluate variables that may impact or be related to intervention outcome. Child and family-specific characteristics (e.g., autism status, language ability, caregiver stress, perceived family support) should be investigated as potential moderators of intervention success. If further investigation yields continued positive outcomes, then providing ways to increase caregiver access to the program would appear needed. Providing easy ways to access the intervention program, whether that be via training other types of providers to implement the protocol (e.g., social workers, psychologists, licensed professional counselors, pediatricians) or finding alternative methods of

delivery (group, telehealth, online website), should also be considered and investigated. Despite these limitations, our outcomes provide preliminary evidence that developing low-cost strategies to address SIB in young children with IDD, should continue. Reducing early, less-severe forms of SIB could have the potential to lead to an improved quality of life for the young child and their caregivers and lessen the likelihood that these behaviors persist into adolescence and adulthood.

Compliance with Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent was obtained from all caregiver participants included in the study for themselves as well for their child.

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Table 1. Participant inclusion and exclusion criteria

Inclusion Criteria ^a	Exclusion Criteria
(1) Adaptive behavior composite score less than or equal to 80 on the Vineland Adaptive Behavior Scales, 2nd edition	(1) Already enrolled in psychosocial intervention or taking psychotropic medication targeted at early SIB
(2) Early SIB, occurring for at least two months at initial screen by parent report and endorsement of behavioral item on Self-Injury Subscale of the Behavioral Problems Inventory-Short Form	(2) Initiated a new non-SIB targeted psychosocial intervention or psychotropic medication within 45 days of enrollment
(3) Total score greater than or equal to 3 on the SIB-specific items (2, 50, 52) on the Aberrant Behavior Checklist	(3) Recent changes in psychosocial interventions (not including changes in treatments due to holidays/sickness/vacation)
(4) Lived with participating parent for at least 6 months.	(4) Child and/or parent was non-English speaking, reading, or writing
	(5) Parent did not agree to complete assessments or intervention

^a Participants were allowed to continue stable interventions (e.g., speech therapy, occupational therapy) during the course of the study, but those interventions were required to have been stable for 90 days prior to treatment.

Table 2. Weekly SIB-PT Topic Outline

Session #	Proposed Pilot Sessions	Session Content & Skills
1	<i>Introduction, Psychoeducation, & Behavioral Model of SIB</i>	<ul style="list-style-type: none"> • Overall goal of program • General overview of SIB in IDD • ABCs/Functions of behavior
2-3	<i>Antecedent Management: Prevention, Safety, and Use of Schedules</i>	<ul style="list-style-type: none"> • Discuss importance of prevention <ul style="list-style-type: none"> ○ Safety precautions and supervision ○ Environmental changes ○ Antecedent interventions • Visual schedules
4-5	<i>Reinforcement</i>	<ul style="list-style-type: none"> • Positive reinforcement • Enriched environments and competing items
6	<i>Functional Communication Skills</i>	<ul style="list-style-type: none"> • Functional communication to replace socially maintained SIB • Developmental stages for communication and social behavior
7	<i>Planned Ignoring</i>	<ul style="list-style-type: none"> • Extinction to reduce SIB • Strategies when extinction is not immediately successful • When to use and when not to ignore SIB
8	<i>Teaching Compliance & Positive Discipline</i>	<ul style="list-style-type: none"> • Limit setting • Clear behavioral expectations • Guided compliance and effective demands/requests • Motivation versus skill deficits • Age appropriate, high probability requests
9	<i>Teaching Skills</i>	<ul style="list-style-type: none"> • Developmental stages of play • Replacement behavior training • Promoting adaptive skills • Analyzing components of a skills • Child-directed play (if possible) • Use of modeling, descriptive commenting, chaining, and errorless learning
10	<i>Flex Session: Toilet Training, Imitation Skills, or Bedtime Routine</i>	Based upon needs of child, one of the four “flex” sessions was added to assist with either a) achieve child’s toileting continence; b) establish a bedtime routine/schedule; c) teaching social/play readiness skills through imitation; or d) focusing on a previous skill
11	<i>Generalizing Skills</i>	<ul style="list-style-type: none"> • Strategies to generalize and maintain positive behavior change

Table 3. Main Demographic Information – Child Participants

Variables	<i>N</i> (%)
Ethnicity	
White	6 (54.55)
Hispanic	3 (27.27)
Black	1 (9.09)
Other	1 (9.09)
Gender	
Female	3 (27.27)
Male	7 (63.64)
Diagnoses	
Autism Spectrum Disorder	4 (36.36)
Intellectual Disability	5 (45.45)
Attention-Deficit/Hyperactivity Disorder	4 (36.36)
Developmental Delay	3 (27.27)
Anxiety	1 (9.09)
Maternal Employment Status	
Full Time	3 (27.27)
Part Time	1 (9.09)
Homemaker	6 (54.55)
Disabled	1 (9.09)
Paternal Employment Status	
Full Time	8 (73.00)
Unemployed	1 (9.09)
Disabled	1 (9.09)
Student	1 (9.09)
Maternal Education	
Some High School	2 (18.18)
Graduated High School/GED	3 (27.27)
Some College/Post-HS cert/2 year degree	5 (45.45)
Advanced Degree	1 (9.09)
Paternal Education	
8 th Grade or Less	1 (9.09)
Some High School	1 (9.09)
Graduated High School/GED	3 (27.27)
Some College/Post-HS cert/2 year degree	3 (27.27)
College Graduate	3 (27.27)

^a Medical history: Obstetric brachial plexus injury and torticollis at birth ($N = 1$); spina bifida, hydrocephalus, chiari malformation, dysphagia, G-tube, neurogenic bladder and bowel, and bilateral clubbed feet ($N = 1$); Marfan syndrome ($N = 1$); seizures with one having Lennox Gastaut Syndrome ($N = 2$); vision problems ($N = 2$); and hearing concerns ($N = 1$). Two children were born premature (28 and 36 weeks). All but one of the children had a language delay. Seven children were on medications (i.e., allergy, seizure, and psychiatric).

Table 4. Main Demographic Information –Parent Participants

Variables	<i>N</i> (%)
Ethnicity	
White	6 (54.55)
Hispanic	3 (27.27)
Black	1 (9.09)
Other	1 (9.09)
Caregiver	
Mother	9 (81.81)
Father	2 (18.18)
Income	
Less than 20K	2 (18.18)
20-40K	4 (36.36)
40-60K	2 (18.18)
60-90K	1 (9.09)
More than 90K	1 (9.09)
Prefer not to Answer	1 (9.09)

Table 5.
Pre- and Post-Intervention Outcomes Across Measures

Measure	Pre SIB-PT <i>M (SD)</i>	Post SIB-PT <i>M (SD)</i>	<i>t</i>	<i>d</i>
<i>Parent Child Observation</i>				
Parent Maladaptive Behavior Index	65.75 (16.60)	23.27 (13.65)	7.03**	1.83
Child Maladaptive Behavior Index	16.00 (13.62)	5.36 (5.61)	2.25*	0.21
Positive Praise (Rate per minute)	0.61 (0.28)	1.06 (0.41)	2.96*	0.34
<i>SIT Scale</i>				
<u>Number Index</u>	<u>0.36 (0.51)</u>	<u>0.00</u>	<u>2.19</u>	
<u>Severity Index</u>	<u>0.45 (0.74)</u>	<u>0.00</u>	<u>2.03</u>	
<u>Overall Risk Index</u>	<u>0.0</u>	<u>0.00</u>		
<i>BPI-01 (frequency scores)</i>				
<u>Self-Injurious</u>	<u>21.75 (11.40)</u>	<u>10.08 (6.05)</u>	<u>5.35**</u>	<u>1.28</u>
Stereotypies	39.25 (21.33)	31.25 (19.97)	3.24**	0.39
Aggressive/Destructive	20.67 (12.29)	14.25 (11.62)	4.31**	0.53
<i>ABC</i>				
Irritability	33.25 (7.79)	17.92 (8.73)	5.79**	1.88
<u>SIB-specific items (N = 3)</u>	<u>5.5 (1.70)</u>	<u>2.75 (1.13)</u>	<u>4.46**</u>	<u>1.90</u>
Lethargy	14.08 (7.91)	8.17 (7.08)	5.85**	0.79
Stereotypies	11.50 (5.72)	7.42 (5.05)	3.92**	0.76
Hyperactivity	32.33 (13.79)	20.42 (14.06)	4.29**	0.85
Inappropriate Speech	2.92 (2.31)	1.83 (2.48)	1.27	
<i>PSI- SF</i>				
Total Stress	76.53 (13.78)	70.45 (14.27)	0.97	

* < p = .05; ** < p = .01

Note: SIT Scale = Self Injury Trauma Scale; BPI-01 = Behavior Problems Inventory; ABC = Aberrant Behavior Checklist; PSI = Parenting Stress Scale-Short Form. SIB specific outcomes are underlined for emphasis.

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